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Amputees' experience and descriptions of phantom phenomena – a qualitative study

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This work is dedicated to Mum and Dad,
who taught us that human beings are worth loving…
but also that they can stand being laughed at

PREFACE

Almost all social work theory is based on the fundamental concepts "relationship" and "verbal communication" (1-3). The primary function of a social worker in a multidisciplinary pain clinic is to understand the meaning pain has in the patient's life, both from an individual perspective and from a sociocultural one. If needed, the social worker will support the patient to change or alleviate psychosocial factors that may interact negatively with in the patient's pain experience (4, 5).

My experience as a social worker required me to search systematically for knowledge that could help broaden our understanding of what pain really meant for the haunted person, as well as what we were really treating when we treated his/her pain. From a social-scientific perspective, symptom scales, surveys, questionnaires and behavioural checklists will not help turn behavioural data into social facts to assist in further understanding the person's thoughts and actions (6-9).

When studying for my MscSw I was able to apply qualitative methodology to clinically-based research questions. I invited patients with chronic pain to describe – in their own words – what their pain meant to them. The material was analyzed and a most important finding was that they all, irrespective of age, gender, reason for the pain or degree of affliction, stated an intense need to understand and explain their own unique pain for themselves. In line with Sayer's (8) terminology and realistic approach to methods in social science I wanted to understand and explain the presence of chronic pain. To me it was also important to note that pain without the attempt to make it comprehensible does not exist (7, 10, 11). One important conclusion from my master's thesis was that a systematic study of the relation between understanding and explaining could perhaps help me to uncover how and why the patient in pain thinks and thereby contribute important knowledge about the significance of pain in an person's life. The study of phantom phenomena including pain in a lost body part, a body part (despite best intentions) surgically removed seemed to be a fruitful entrance-ticket to such structural research.

ABSTRACT

In phantom phenomena, pain and/ or other sensations appear to be experienced from amputated body parts. The phenomena have long been the object of research and their underlying mechanisms have been discussed over the years. The condition is not specific to amputated limbs, having to a lesser extent been reported after radical surgery in other amputated body parts such as the breast. The phantom limb phenomenon is a well-documented, post-operative pain condition, but phantom breast phenomena are less documented. Multi-causal theories are used when trying to understand these phenomena, recognising them as the result of complex interaction among various parts of the central nervous system. This has been confirmed through studies using functional brain-imaging techniques. There is a wide range of treatment methods but no documented treatment of choice. In particular, there is a lack of knowledge about how amputees experience the meaning and consequences of their phantom phenomena.

The overall aim of the work presented in this thesis was thus to elicit and understand how amputees describe their phantom experience in everyday words, and how far their descriptions are influenced by different sociocultural factors. The approach adopted complements existing, predominantly neurobiological, knowledge.

The work is based on a two-year, prospective, explorative interview study with 28 women and men who had undergone limb amputation or mastectomy. The focused, narrative-oriented interviews were transcribed verbatim and the scripts were analysed with a combination of narrative and discourse analysis (Studies I and II). Content analysis was used for Studies III and IV. The approach in Study II was longitudinal, since all the four interviews with the eight women (out of the 28 sample) who had undergone mastectomy were analysed. In Studies I, III and IV only the interviews collected one month after the amputation/mastectomy were used. One month after the amputation 22 out of the 28 interviewees described and related their phantom pain and or phantom sensations in sensory-discriminative, motivational-affective and cognitive-evaluative dimensions. The phantom sensations were experienced mainly as more agonizing than the phantom pain, while the phantom breast phenomena differed from classic phantom extremity phenomena, not seeming to cause much distress. Further, the interviewees reported the importance of rehabilitation and advances in prosthetic technology. Loss of mobility struck older amputees as loss of social functioning, which distressed them more than it did younger amputees. Thus, when phantom phenomena were described as everyday experience, they become a psychosocial reality, which made it possible to find out *what* in the interviewees' phantom experience constituted suffering. The findings supplement the definition of phantom phenomena in scientific literature and clinical documentation.

In conclusion these findings highlight the importance of approaching the phenomena on an individual basis as a process of evaluation and selection. In addition, experience and understanding of the phantoms have sociocultural aspects. There follows the need for individualized communication and information from the clinician, and for incorporating a meaning-centred approach in future studies. The present insights may also be of value in other iatrogenic pain conditions.

List of Publications

I **Björkman B**, Arnér S, Lund I, Hydén L-C
Adult limb and breast amputees' experience and descriptions of phantom phenomena – A qualitative study
Scandinavian Journal of Pain 2010; 1: 43-49

II **Björkman B,** Arnér S, Hydén L-C
Phantom breast and other syndromes after mastectomy: Eight breast cancer patients describe their experiences over time: A two-year follow-up study
The Journal of Pain 2008; 9: 1018-1025

III **Björkman B,** Lund I, Arnér S, Hydén L-C
Phantom phenomena – their perceived qualities and consequences from a patient's perspective
Scandinavian Journal of Pain (In Press)

IV **Björkman B**, Lund I, Arnér S, Hydén L-C.
Potential suffering related to phantom phenomena following amputation or mastectomy
(In manuscript)

Content

Berit Björkman

”Men nu har Gud insatt lemmarna i kroppen, var och en av dem på det sätt, som han har velat. Om åter allasammans utgjorde en enda lem, var funnes då själva kroppen? Men nu är det så, att lemmarna äro många och att kroppen dock är en enda. Ögat kan icke säga till handen: ”Jag behöver dig icke”, ej heller huvudet till fötterna: ”Jag behöver eder icke.”

I Korinterbrevet 12: 18 t o m 22

INTRODUCTION

GENERAL BACKGROUND

The puzzling phantom phenomenon is a state where some patients after an amputation still experience the lost body part as persistent in form, position and sometimes even voluntary movement (12-15).
Phantom pain constitutes one distressing modality within phantom phenomena, which is often long-lasting (16, 17) and for which still no evidence-based treatment of choice exists (18).
In the Western countries the phantom sensation, another modality of phantom phenomena, is seen as an un-wished-for, but commonly occurring, consequence of amputation. However, during the past six decades the phenomena have been in focus for evaluation in various scientific disciplines (12, 19, 20).
The work reported in this thesis attempts to broaden our view of phantom phenomena through observing and evaluating them from a social perspective. Here human beings are seen as social persons, whose experience, describing and managing their course-of-life events, is always imprinted in a defined socio-cultural context (6, 7, 21-23). Such research is meaning- and understanding-oriented and is practised within disciplines such as sociology, anthropology, ethnology and social- and narrative psychology (7, 8, 21, 22, 24). However, we still lack documentation concerning phantom phenomena from such a perspective.

PHANTOM PHENOMENA FROM A HISTORICAL PERSPECTIVE

The first known description of the phenomena in medical text was given by Ambroise Paré, a prolific military surgeon, in his work on surgery and trauma in 1551 (25).

"For the patients long after the amputation is made, say they still feel pain in the amputated part. Of this they complain strongly, a thing worthy of wonder and almost incredible to people who have not experienced this" Paré quoted (25), p.76.
The first author to give the phenomena a name within the medical sphere, however, was the neurologist Silas W Mitchell (26). 300 hundred years later, Mitchell also acquired his experience and knowledge from battlefield victims during the American Civil War (25, 27), when he was assigned to the Philadelphia Hospital to treat men with nerve injuries following gunshot lesions of major nerves in the limbs (25, 28).
Since the experience of a phantom limb is considered rather the rule than the exception (25), the phenomena have been acknowledged since ancient times and mentioned and discussed in folklore and folk wisdom (25, 27). Thus Admiral Lord Nelson stated that the phantom fingers of his amputated arm gave him "... a direct proof of the existence of the soul" (15, 25). The literature contains speculations on the reasons for this over-three-hundred-year "medical silence" (25, 27), one being the phenomenon's idiosyncratic character (25, 29), which has made it both incomprehensible and untrustworthy. Before Mitchell published his scientifically groundbreaking article "Phantom Limbs" (26), he submitted his initial description anonymously to the Atlantic Monthly (1866) as a story entitled "The

Case of George Dedlow". His approach has been interpreted as indicating reluctance in medical culture to accept and regard the phenomena as not a physical reality but more as 'fictive limbs' (25, 29). Behind this "medical silence" there existed "an amputees' reality" about which our modern age could learn only through composed stories in fictional and historical literature such as The Case of George Dedlow (28). We can grasp facts about what the military surroundings meant for development of surgery and for the technological advancement of artificial limbs such in large national investigations as the Investigation upon the nature, causes and treatment of hospital gangrene as it prevailed in the confederate armies, 1861-1865 (30) or Analysis of four hundred and thirty-one recorded amputations in the contiguity of the lower extremity (31). But what these facts and these circumstances really meant for the experience of the phantom phenomena can be envisioned by reading contemporary novels such as Tolstoy's (32) and Zola's (33) with their descriptions of the awful pain, horrific emotions and other extended consequences an amputation involved for wounded soldiers at that time.

THEORETICAL FRAMEWORK

Definition of pain

Pain has been defined as:

> "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Pain is always subjective. Each individual learns the application of the word through experience related to injury in early life." (34)

The 30-year-ld IASP definition of pain (1979) is rooted in the biopsychosocial model, which takes account of the effects of psychosociocultural factors on how patients experience their symptoms and how their experience emerges in the clinical situation (35).
The gate-control theory of pain mechanisms has had a profound influence on pain research (11, 36, 37). The theory drew attention to the dynamic and plastic components of pain sensations and its modulation but focused on its clinical aspects. This became possible since the theory postulated that all pain signalling in the spinal cord is in a complex interaction with afferent and efferent signals but subordinate to the function of higher brain areas. Thus psychological factors such as past experience and emotions would influence the perceived pain by acting on the gate control in the spinal cord (36, 37).
This knowledge also resulted in worldwide development of multidisciplinary pain clinics for pain analysis and treatment, including psychologists and social workers in their professional teams (36, 37).

Phantom phenomena in the evidence-based discipline

The question "What is the phenomenon" (38), p. 251 has constituted the basis for numerous investigations, no matter whether the research focus has been: (i) to define phenomena in discrete categories distinguishable from other co-existent pain conditions; (ii) to examine the measurement of phantom-limb pain and related phenomena; (iii) to investigate from prevailing bases of knowledge hypotheses about the causal mechanism of phantom-limb pain and/or different possible models of treatment (12).

Prevalence and modalities

Post-amputation phenomena include three categories: phantom sensations, phantom pain, and stump pain (12, 18, 39). Phantom pain has a reported incidence of 60%–80% among adult amputated patients (12, 39-41), and two years after limb amputation it can still be 60%–75% (17, 18). The prevalence of phantom sensations among limb amputees is reportedly almost 100% but fades over time (12, 40, 41). Phantom sensations have most often been described as non-painful, exteroceptive sensations as well as super-added components (12, 39, 42). However, numerous patients describe their phantom experience as a general awareness of the presence of the limb rather than specific somatic sensations (20, 43, 44).
In the past few decades, a more distinct differentiation, between the concept of somatic sensations and the concept of corporeal awareness, has developed regarding both phantom limb phenomena (39, 45) and phantom breast phenomena (46, 47). Stump pain, i.e. pain in the residual limb, is reported in about 50% of amputees (12, 18, 19). Most previous studies have not explicitly and prospectively differentiated between these types of phenomenon, leaving the prevalence of each phenomenon still in dispute (39, 48). Phantom phenomena are not specific to limbs, also being reported but to a lesser extent after amputation of other body parts such as breast, genitals, rectum and teeth (20, 47, 49). Breast phantom phenomena are the second most studied after limb. Regarding breast phantom phenomena the prevalence varies substantially compared with that of the limb, ranging from 10% to 66% (47, 50-53) but have also been described as long-lasting, i.e. two to six years (46, 54-56). Simmel (52), one of the first scientists to focus on breast phantom phenomena, reported that" The essential difference between the limb phantom and the breast phantom is one of vividness and articulation – in the literal and metaphorical way" (ibid., p. 346). This difference has been confirmed in several later studies (46, 53, 54).
Amputation is not the only condition to induce phantom phenomena; they may also arise after epidural blockades (14, 57). Further, injuries and lesions in peripheral tissue, spinal cord injuries and strokes with damaged brain tissue can cause analogous phenomena (13, 15, 58-60).

Causal explanations of phantom phenomena

Early theories and explanations of phantom limb pain were grounded entirely in peripheral factors (12), suggesting for example that the severed nerve-ends at the stump would grow and develop into painful nerve ganglia: neuromas (14, 38, 61). The limitation of this physiological model of explanation became evident, when pain research advanced and treatment proved unsuccessful. Clinical practice and study results showed that the universal characteristic of a phantom phenomenon was that it was reported as an integral part of the body (14, 20) and hardly solely dependent on the neuroma activity itself.
The models of explanation developed gradually from spinal-cord mechanisms to focus on processes in higher brain areas and concepts such as *body schema* and *somatosensory pain memories* became current (12, 14, 15, 44, 52, 57, 59).The proposed difference between the characteristics of breast phantom phenomena and limb phantom phenomena has, from their mechanisms, been that the breast has relatively smaller somatosensory cortical representation and an absence of kinaesthesia (47, 50-52, 62). However,Melzack, (13), p. 92 found that the phantom phenomena presuppose a more complex and interactive cerebral functioning than the somatosensory system can constitute, thereby emphasising individual character of the pain experience and its many different aspects.

The unintelligible character of the phenomena early on made psychological models of explanation relatively common (38, 58, 63-65). Unintelligible, since it was not "real and stable in a culture that stresses the physical, ontic aspects of human existence" (29), p. 214, and since there was no answer to such questions as; "How is it possible to feel pain in a body part that has been surgically removed (66), p. vii. Often the same psychological theories and concepts have been used as for chronic pain conditions:
"... personal disorder; masked depression; guilt; childhood deprivation or trauma; defence against loss; repressed hostility and aggressions… pre-existing personality" (12), p. 134. The literature is very complex and sometimes even contradictory (12, 61). Katz, p. 290 summarizing the co-existence of depression and phantom pain as comprehensible, and the "... prevalence of pain of psychological origin among amputees and general population", as non-existent.

Today, multi-causal theories are used when trying to understand phantom phenomena. They recognize the complex interaction among activity in various parts of the central nervous system: the periphery, the spinal cord and the brain (14, 18, 44, 67). Studies that use functional brain imaging technologies have verified that brain areas are interrelated in a very complex way concerning phantom limb experience (20, 42, 44). Use of these technologies has important results but these do not tell us enough about phantom pain as a subjective experience in clinical settings (68).

What is missing from evidence-based knowledge of phantom phenomena?

While important results have been achieved they are not necessarily related either to clinical experience or to the associated suffering of phantom pain, and successful treatment options remain limited (13, 18, 27, 49, 69). The characteristics of phantom pain and or phantom sensations are not uniform among amputees (19, 46, 61, 69-71) and this complex nature of phantom phenomena and their multifactorial bodily surroundings make interpretation of the results ambiguous as regards both prevalence and co-existent suffering (39). Thus even residual phantom pain reportedly causes considerable suffering (14, 40). Other studies establish that the degree of distress and disability associated with phantom phenomena has seldom been formally assessed (18, 19, 42, 72).

Methodological problems

The methodological approaches used to evaluate these multifaceted phenomena are also fraught with problems since the choice of research design and assessment methods will influence the reported prevalence and distress (12, 50, 73). Hill (12), p. 129 noted that "the proposed mechanism is almost impossible to operationalize and test" and also that the shortcomings of customary scientific methods, within the consensus of "cortical reorganization following amputation", in terms of capturing and analyzing pain perception are always "directly related to the individual's unique history…" (ibid., p.131).
Studies with a biopsychosocial perspective (16, 74, 75) have sought to identify good and/ or bad adjustment strategies for phantom pain, with assessment instruments or questionnaires and criterion measures of variables such as depressive symptoms, pain inference in daily activities, and psychological distress as well as descriptions of cognition, coping responses and/or social environments (16, 74, 75). However, evaluation instruments often constitute

a group-level estimation and while they can be useful as screening instruments they have limited clinical application when the individual variations are often not accounted for (16, 39, 57, 72, 76, 77).

A social-scientific approach to the definition of pain

It is common for a social-scientific perspective to include and consider the influence of social institutions, e.g. health care systems, on the individual's experience and action that are to be analyzed and understood (6, 7, 22).

Further, it is here fundamental to regard human beings as able to act and to evaluate the purpose and the consequences of their actions. These abilities do not terminate where the person acts as a patient or as a study participant. From a social- scientific perspective a person creates his/her identity and generates meaning in his/her life in interaction with other people (78, 79). From this perspective pain is not regarded essentially as a disease-oriented symptom but as a part of the life process (6, 80-82). During the whole process language is active as an instrument for understanding and for creating relationships (6, 7, 23, 83).The abstractions and metaphors we use in discourse have been drawn from and created in language, established in the culture and the time-epoch we are living in. The scientific issue then becomes to understand how individual and social actions emerge and become meaningful.

A very important aspect is then that both knowledge and science are "not a thing but a social activity" (8), p. 16 with the consequence that the social scientist must understand the "meaning" of the behavioural data recorded, so as to turn them into social facts (9), p. 28.

Aims and Research questions

The overall aim of the work presented in thesis was to elicit and understand how amputees describe their phantom experience in everyday words, and how far their utterances are influenced by different sociocultural factors, adopting an approach that complements existing, predominantly neurobiological, knowledge. The four studies listed below chart the process of realising this aim.

Study I: The specific aim was to explore the ways patients describe and evaluate their phantom pain/phantom sensations when they attempt to give meaning to their experience.

Study II: The specific aim was to explore women's personal descriptions of whether and how breast-phantom phenomena appear after breast amputation (mastectomy).

Study III**:** The specific aim was to describe and discuss how patients experience and interpret their post-limb amputation or post-breast phantom phenomena. Of special interest were how patients evaluated the perceived qualities of the phenomenon itself, how different aspects (both physical and/or sociocultural) influenced the existence of the phenomena, and how their consequences affected their everyday lives.

Study IV: The specific aim was to identify and describe the patients' suffering related to, and as a part of, the post-amputation psychosocial situation.

”... Ciprano Algor reflekterar runt den korta tid han stannat där,
3 minuter… Jämför man med den ögonblickliga hastigheten
hos tanken, som fortsätter i rät linje tills den verkar ha tappat
kompassriktningen, det tror vi därför att vi inte uppfattar att
när den löper i en riktning rycker fram åt alla håll, jämför man
den med ordet, sade vi, så måste det stackars ordet ständigt be
den ena foten om lov för att få den andra att gå, ändå snavar
det jämt, tvivlar, roar sig med att svänga runt ett adjektiv,
en verbtempus som dök upp utan att låta sig tillkännages av
subjektet …”

José Saramago, Grottan, 2000

METHODS AND PARTICIPANTS

Since the general ambition was to study the participants' phantom experience after an amputation/mastectomy "as a social reality apart from the conception and definition of illness as formulated by biomedicine" (6), p. 52, the methodological approach had to shift the perspective on the phantom phenomena from "the voice of medicine" to "the voice of the life world" i.e. listen to and analyze the discourse of amputees when they, within this pain-producing situation, were allowed to use their own words and individual associations (6, 84).

Qualitative research methods are useful for studying human and social experience (85-87). Focused interviews with open-ended questions for small samples of individuals exposed to the same event or involved in the same situation constitute one such method (84), p. 99. Such methods are more suitable for the present purpose than survey research using mainly fixed-choice questions for random sampling. The focused interview makes it possible to account for individual variations both in subjective pain experience and in interactions of social processes (84, 87).

Given the scarcity of prospective and longitudinal studies, a prospective, longitudinal two-year follow-up approach was selected. Participants were interviewed on four occasions: one month; six months; one year; and two years after the amputation. The interviews were totally detached from a medical context and standard medical check-ups. They were conducted in the author's (BB) office or in participants' homes.

An overview of the four studies is presented in Table 1.

Table 1

Overview of the four studies reported in this thesis: a two-year follow-up project with a prospective, explorative and qualitative design

	Study 1	**Study 2**	**Study 3**	**Study 4**	**For the Future**
Design	Interview study: Narrative-/ discourse-oriented analysis	Longitudinal interview studies: Narrative-/ discourse-oriented analysis	Content analysis applied to transcribed interviews	Content analysis applied to transcribed interviews	Content analysis applied to remaining transcribed interviews
Number of participants	28 (16 women, 12 men)	8 (women)	28 (16 women, 12 men)	28 (16 women, 12 men)	The 28 - less the departed.
Cut-off time/s	1 month after amputation/ mastectomy.	1 month, 6 months, 1 year and 2 years after mastectomy	1 month after the amputation/ mastectomy	1 month after the amputation/ mastectomy	6 month, 1 year and 2 years after the amp/ mast

STUDY PARTICIPANTS

During September 2002 to October 2003, potential study participants were recruited at a tertiary university hospital in an urban area. They were asked to participate when the decision to amputate was made (for obvious reasons, recruitment had to vary for traumatic amputees). Selection was made consecutively, in cooperation with coordinators from the medical units involved. Study participants' situations were categorized as follows: (i) amputation related to complications of diabetes mellitus and vascular diseases (from endocrinology clinic); (ii) amputation after cancer diseases (from orthopaedic, oncology and breast surgery clinics); and (iii) amputation necessitated by trauma (from general surgery, orthopaedic, anaesthesiology, and intensive-care clinics). Inclusion criteria were: (i) Swedish-speaking; (ii) between 18 and 80 years of age; and (iii) first amputation. Gender and age distribution in each group were accounted for.

The purpose of including different causes of amputation, both genders and a wide range of age was to extract as much information as possible on how the interviewees described and experienced various aspects of phantom phenomena.

Given the different causes of amputation and procedures in the medical units involved, some variations emerged in the time when interviewees were contacted by the coordinators. The interviewees were invited to participate either: (i) on the day of the decision to amputate (complications of diabetes, vascular diseases and cancer diseases); or (ii) ten days after mastectomy at the first medical check-up; or (iii) a few days after waking up from surgery (trauma). Some difficulties in recruiting post-trauma-amputated patients for the studies were noted, and the recruiting area was thus expanded to include three other hospitals in the same region; one with a hand-surgery clinic. To avoid preconceptions the interviewer did not check the interviewees' medical records before the interviews or during the analyses.

Of 34 potential participants approached, five declined. One young woman with a traumatic amputation and complications was excluded. The remaining 28 participated in the study.

After the Regional Ethics Committee of Karolinska Institutet had approved the study, potential participants were personally informed of the study aims and given an outline of the type of information the researchers were seeking. All study participants gave their oral, informed consent to participate. Details of the measures taken to ensure anonymity and a clear statement of the voluntary nature of participation were also included.

DATA COLLECTION AND DATA ANALYSIS

Data collection (Studies I, II, III, IV).

The present author (BB) conducted all the interviews, which lasted approximately one hour each. The interviews focused on four general areas: amputation as a life event; living with a lost body part; possible phantom phenomena, i.e. sensations and/or pain; and other types of pain. These areas constituted the structure of the interview, in which the interviewer could pose additional questions when an area was not dealt with satisfactorily or when descriptions were insufficient. The author (BB) recorded and transcribed (verbatim) the interviews, omitting non-verbal communication such as sighs and pauses.

Data analysis

The transcribed interviews were the main data source for all the four studies but, depending on the aim, associative question formulations and/or the "cut-off-time", the way of analysing the transcribed material changed within the process (see Table 1).

Data analysis – Study I

Interviews with focused, open-ended and narrative-oriented questions that encourage "free talking" will include question-and answer exchanges, accounts, narratives and other forms of discourse (88-90). Because any illness constitutes a disruption, a discontinuance of ongoing life (6, 91), it is very usual for interviewees in such contexts to narrate their experience to re-create meaning (88-90). A classic definition of a narrative is that it shall be structured with a beginning, middle and end (89), but over time the approach to what a narrative is and how it will be analysed has became more pragmatic: Narration is only one aspect of communication, there are also other discourses important to analyse (88, 90).

After the interviewer (BB) had repeatedly re-read the transcripts – often while listening to the recorded interviews (89), the transcribed interviews were analyzed using a method combining discourse analysis (87, 92) and narrative analysis (6, 89-90). Discourse analysis refers to theories and methods used for studying the organization of talk and text (87). Such an analysis seeks to understand how language is used when conveying "information about the world, ourselves, and our social relationships" (92), p. viii.
With another researcher (LCH), the interviewer performed a three-phase analysis. Phase I involved getting an overview of all data and extracting descriptions and narratives in which the interviewees focused on the four areas. Phase II focused on identifying and extracting communication devices used by the interviewees (81, 82, 93, 94). These were mainly, descriptions and metaphors that produced animated images of how something felt (95). Phase III involved compiling all the interviewees' descriptions, metaphors, and narratives into one analysis, which revealed that they used the communication devices to compare, to draw parallels, and to demonstrate individual knowledge about various factors related to the phantom experience and how they understood the phenomena.

Data analysis – Study II

The method to analyse the interviews of the eight women with a complete mastectomy, was the same as in study I. However, since this was a follow-up study with a time-perspective the analysis was made in four phases instead of three.
Phases III and IV were implemented to gain understanding of any changes over time that the women experienced in the phantom breast. In phase III each woman's comments from all four interviews were placed beside each other and compared over time. In phase IV, the material from the four interviews was used for the women as a group. Here excerpts from each of the four interviews with all the women were combined in four separate groups and compared over time. A comparative analysis was then done for each interview period.
Then, using discourse analysis the researchers could identify how the interviewees estimated their experience in daily life and how this experience changed over time.

Data analysis – Study III

In Study III Thematic content analysis (87, 96, 97) was selected as an appropriate method for systematic coding of the content from the transcribed texts. This type of content analysis allows systematic comparison of differences between individuals and of individual differences/changes over time (96).
Inductive coding (96, 98) was used for analysing the information from the interviewees' responses to the open-ended questions. The analysis took place in four phases: (i) the interviewees' descriptions of phantom phenomena and their consequences. Sociocultural factors of note, and descriptions of attitudes and expectations, were coded as themes. Some 50 themes were identified as relevant; (ii) These themes were grouped into 43 categories adequate for the present purpose of study; (iii) To demonstrate intra- and inter-individual differences, the contents of some of the categories were graded into either variations of intensity or differences in phrasing; (iv) In the last phase a coding form was created to cover all the 43 categories, and used for coding all the interviewees' responses. Emerging problems or uncertainties were resolved through discussion among the researchers.

Data analysis – Study IV

Study IV also used thematic content analysis (87, 96, 97) as an appropriate method. A coding form, elaborated in Study III (99) was used to code all the interviewees' responses. The elaboration of this coding form had taken place through inductive coding (96, 98) and incrementally in analytical steps (99). First the interviewees' descriptions of phantom phenomena and their consequences, sociocultural factors of note, and descriptions of attitudes and expectations, were coded as themes. Then these themes were grouped into content categories deemed adequate for the purpose. The analysis focused on the categories in the coding form that dealt with sociocultural factors, attitudes to and expectations concerning the amputation itself. To demonstrate intra- and inter-individual differences, the contents of some of the categories were graded into either variations of intensity or differences in phrasing. Emerging problems or uncertainties in this analysis were resolved through discussion among the researchers.

RESULTS

STUDY I

The analysis revealed that, one month after the amputation/mastectomy, the interviewees used the communication devices to compare, to draw parallels, and to demonstrate individual knowledge of how to experience and understand phantom phenomena. These factors were – in one way or another and at one time or another – present in all the interviews and were important for understanding the experience of phantom pain and phantom sensations in an everyday context.

With one exception there were no conceptual problems in talking about the perceptions of phantom phenomena. Most of the interviewees had good knowledge of phantom phenomena. With their varied wealth of vivid details, the interviewees gave a convincing picture of the phenomena as an integral part of themselves. In their descriptions the phantom sensations appeared more uncomfortable and stressful than the phantom pain.

When attempting to understand and describe their unique, extraordinary phantom experience, their former experience of a vivid body, perceived as functioning wholeness, an instrument for action, constituted important support. It became apparent here that rehabilitation and advances in prosthetic technology were very important for them, as offering a possibility to recapture former capacity.

Women who had undergone mastectomies described phantom phenomena differently from limb amputees and were less informed by health care professionals about such consequences. Also, there were differences between the age groups' descriptions of the consequences of amputation. The younger had a greater confidence in their physical capabilities, such as better balance, sight and strength. They could more effectively assimilate the rehabilitation programme. For older interviewees, the loss of a bodily function made them sad and more anxious about the future.

The findings of Study I highlight the need to listen carefully to the patients' own descriptions, both in clinical and scientific settings (with more qualitative studies) to find out what functional losses or life change patients fear the most. Further, it would be appropriate to focus more on older patients.

STUDY II

Given the lack of clinically important knowledge and the findings from Study I, the eight women with breast cancer in the present study were selected from the total sample of interviewees and were followed-up for a further three interviews (see Table 1). Four (50%) experienced some type of phantom-breast sensations and phantom-breast pain. When phantom breast sensations and or phantom breast pain were present they had been so from the beginning. The women's initial narrations suggested that phantom breast sensations and phantom breast pain were perceived in a complex context and that they coexisted with a continuum of other altered sensations and sensation disorders. Aside from the postoperative sequels and painful iatrogenic neuropathic pain complications of surgery, the women also experienced other iatrogenic side effects of chemotherapy, radiotherapy or endocrine therapy.

The descriptions of phantom-breast phenomena varied not only when comparing how phantom-limb phenomena are usually described (where vividness plays a key role), there were also inter-group variations between the women with any observed phantom-breast phenomena. Half of the group used metaphors in their descriptions, which resembled those commonly used in descriptions of the experience of phantom-limb phenomena. The other half had to search hard for the right words, when trying to describe their phantom phenomena as correctly as possible. Concerning the form and localization, the phantom breast continued to be experienced as remarkably formless in its lodging of the phantom breast sensations and phantom breast pain. The only exception to this lack of vividness was one woman with a phantom nipple: "… so palpable that she could hold it between her fingers and scratch away the itch".

All the women experienced some degree of mourning at the loss of the breast, and in all descriptions of their experience their cancer played a major role.

During the temporal course of the study both the experienced phantom-breast phenomena and other sensory disturbances were evaluated in different ways at various time points. The word pain could retrospectively appear in their descriptions, when it in an earlier interview it had been negated as non-existing.

The findings in Study II indicate that: the phantom breast phenomena constituted only one piece of the puzzle; the women's expressions did not refer to the function or loss of function but more to identity and emotion; there could be an inherent communicative problem with women with phantom-breast phenomena, since they are relatively unknown and vague in nature. These circumstances should be considered in research and clinical practice.

STUDY III

Since, the findings from Studies I and II indicated that phantom phenomena did not seem to be an isolated entity, but rather an experience evaluated in relation to coexisting conditions of discomfort and to both previous and later events, the need emerged to penetrate, in more detail, these individual evaluations of the phenomena: sociocultural issues in actions; and possible consequences for the amputees' /mastectomies' everyday life.

One month after the amputation/mastectomy 22 of the 28 interviewees (table 1), experienced phantom phenomena (table 2). For 20 of the 22, phantom pain and phantom sensations were accompanied by proprioceptive perceptions of the lost body part.

Table 2. Prevalence of phantom pain and phantom sensations one month after limb amputation or mastectomy.

	Phantom pain		
Phantom sensation	Yes	No	Total
Yes	16	5	21
No	1	6	7
Total	17	11	28

All the interviewees were able to distinguish and describe both phantom sensations and phantom pain, and to isolate what distinguished them from other, coexistent, pain conditions. Seven interviewees described their stump pain as more intense than their phantom pain. But the presence or absence of stump pain seemed to lack substantial influence on the perceived

intensity of phantom pain. A majority of the interviewees retrospectively described their pre-amputation pain as substantially interfering with their former life.
The interviewees described and related their phantom pain and phantom sensations in sensory-discriminative, motivational-affective and cognitive-evaluative dimensions. The phantom sensations were experienced mainly as more agonizing than phantom pain. Despite both the high intensity of and high annoyance with the phantom pain and phantom sensations, a majority felt that the phenomena were not a hindrance in their attempts to recapture ordinary life. Also, when the hindrance was evaluated as high, the annoyance was evaluated as the highest possible for both phenomena or for the phantom sensations alone, never for phantom pain alone.
The interviewees' reported attitudes of being hindered were also described and estimated in the light of their sociocultural circumstances. Thus, other preceding and/or co-existent pain conditions as well as factors such as pre-operative information, the interviewees' views on pain treatment, and their knowledge and understanding of phantom phenomena were mentioned and related to the pain-producing situation. Rather a scattered, but clinically worthwhile, picture emerged.
Together the findings from this study elucidated the importance of observing the individual approach to the phenomena as an on-going process of evaluation and selection. Equally important is the awareness that experience and understanding of phantom phenomena have sociocultural roots.

STUDY IV

The findings from Study III, where the interviewees evaluated the phantom phenomena as no hindrance, coincidentally relating descriptions of hope, misgivings, social support to the descriptions of the amputation/mastectomy itself, pointed to the amputation/mastectomy as a life-change event. Such signals were also given by the findings from Studies I and II, where the interviewees described the significance of their lost body part.
Thus, the theoretical model of amputation/mastectomy as a disruption of ongoing life appeared as a meaningful basis for s more comprehensive understanding of suffering as a part of the post-amputation situation.
Several individual factors and circumstances contained elements that may contribute to the interviewees' suffering or increased vulnerability.
The majority of the interviewees, 20 of 28, were also burdened with one or more other chronic diseases. The sense of being mentally prepared, or not, seemed to be of crucial significance. Sixteen interviewees described themselves as mentally prepared for physical loss of their body part. Most had experienced a relapse of an earlier cancer diagnosis and/or fatal progress of vascular or cancer disease. Nine were not mentally prepared. Most of those described their experience of decision-making and information-giving as situations of emergency and chaos. Also, at that moment, most of them were not at all ready for the decision to amputate.
Thirteen of the 22 interviewees that evaluated the support from the medical staff expressed some or much disappointment with the communication and/or the relationship with the staff during the amputation process (for instance, lack of communication among the care units involved, too much responsibility for their own care).
Twenty-two of the 28 interviewees experienced phantom pain and/or phantom sensation in their lost body part. Of these, 20 ascribed the same properties to the missing body part as to

their intact part concerning size, shape and posture. The corporeal awareness they described was associated with the descriptions of physical function and/or the importance of the lost body part for what it had meant for them as persons. For 19 of the 28, the descriptions of the lost part were related to at least one important everyday function.
Totally, 15 of the 28 interviewees described the importance of the lost body part for their own personal identity. As many as ten related the loss of both physical function and sense of identity directly to the loss of the body part.
All the interviewees described the various everyday consequences of their post-amputation situation as life-changing: changes in living conditions; the need for rehabilitation; the importance of a social network; and emotional and social support from other people.
Almost all the interviewees described their attitudes towards the disruption of their life caused by the amputation. Three sets of attitudes were identified: (i) the need to adapt to the new situation; (ii) defining the amputation as a challenge to be mastered; and (iii) an inability to adapt to the new situation brought about by the amputation.
The interviewees described 22 different strategies they used to handle their new life situation. Three different categories were identified: making the situation comprehensible; manageable; or meaningful. Twenty interviewees mentioned strategies belonging to all three categories.
Altogether, the present findings highlight the following. 1) Information about a required amputation or mastectomy, given in advance by the doctor primarily responsible for the case, did not always ensure that the interviewees felt mentally prepared. 2) Irrespective of what body part was amputated, its loss for many implied not only a loss of function but even a great loss of identity, and from this perspective the amputation appeared as a unique surgical context, which could inflict particular and extended consequences and suffering on the interviewees.
The study has uncovered psychosociocultural factors and/or combinations thereof, which could be precarious and threatened to make some individuals vulnerable in their social surroundings.

Vi äro på alla sätt i trångmål, dock icke utan utväg;
Vi äro rådvilla, dock icke rådlösa;
Vi är förföljda, dock icke givna till spillo;
Vi äro slagna till marken, dock icke förlorade

Andra Korintierbrevet 4: 8 - 10 .

DISCUSSION

Phantom pain and pain sensations experienced in amputated body parts are well documented post-operative conditions (49). They can be long-lasting (16) and, despite a wide range of pain treatment methods, there is no evidence-based treatment of choice (18).

The starting-point for the present work was that: (i) sociocultural factors have significance for how phantom pain is experienced; (ii) speech constitutes only one inherent potential for communicating an experience of pain from one human being to another (11, 34, 81-83); and (iii) from this perspective there is a lack of knowledge concerning the meaning and consequences for amputees. The present aim was to add to and deepen such knowledge.

In aggregate, the present four studies showed that: (i) amputees have the capacity to describe and to differentiate their phantom experience, and its meaning and consequences for their everyday life; and (ii) to describe different sociocultural issues related to this meaning and consequences.

Some of these sociocultural issues will be discussed here. Hopefully this will bring forth worthwhile knowledge to enhance understanding of the individual experience of phantom phenomena.

HOW THE INTERVIEWEES COMMUNICATED THEIR PHANTOM EXPERIENCE

When given time and interest to describe their phantom experience the majority of the interviewees had no difficulties in distinguishing between phantom pain, phantom sensations, stump pain and other co-existent pain conditions. Even the women with breast cancer, despite their more vague and indifferent phantom experience, had no problems with this differentiation between various forms of pain and sensations. The interviewees' modes of expression showed that their descriptions and narratives, while taking place under particular conditions, in this case interviews, were " social actions" (78). Their use of language as a 'speech act' (100) was made visible. The interviewees chose to compare their phantom experience with earlier and other pain conditions, to draw parallels with similar circumstances and to demonstrate their knowledge of different issues related to the phantom phenomena (Studies I, II, III, IV). "Thus, the words in their talk had an analogous (or 'as if') meaning" (95, 101, 102). During the interviews, the interviewees' descriptions and evaluations laid bare the following findings: (i) the phantom sensations were nastier than the phantom pain (Studies I and III); (ii) despite the perceived high intensity of and high annoyance from the phantom pain and phantom sensations, the phenomena were seldom seen as a hindrance to recapturing a normal life (Study III).

Owing to the less vivid character of the phantom breast phenomena, and the women's difficulties to describe their phantom phenomenon spatially, a possibly masked communicative problem was uncovered. Perhaps it could be problematic and a little shameful to be the first to mention their experience of the phenomenon to a member of care staff. Only one woman with breast cancer had been informed by her physician. None, while referring to breast phantom as a small problem, had talked with her physician about this experience. For one woman with many other diseases and psychosocial problems, however, participation in the study with access to

information about the phenomena, constituted a support for her belief that she was not "mad" (Study II).

The interviewees' descriptions of being both mentally prepared and feeling ready for the decision to amputate indicated an important difference between these two mental conditions. Depending on the preceding case-history, the interviewee could be mentally prepared but also feel totally unready when the amputation/mastectomy became an inevitable reality (Study IV). From the interviewees' perspective the 'information' was not a one-dimensional concept. It could be heard (or not heard), understood (or not) and evaluated within a cascade of experience and feelings (Study IV). As described by (101), p. 58 it is important for the medical profession to realize that patients' verbal descriptions related to pain-producing situations:

> "...represent a judgement based not only on sensory and affective qualities, but also on previous experiences, capacity to judge outcome, and the meaning of the situation."

THE AMPUTATION AS A DISRUPTION OF ON-GOING LIFE

It was evident from all the four studies that the amputation/mastectomy constituted a disruption of on-going life (6, 91). Irrespective of former serious diseases, complicated state of current disease and/ or relapses, the majority of the interviewees described the amputation/mastectomy as a disruption of "taken-for-granted assumptions" and as a pressing need to mobilise different resources "in facing an altered situation" (91), p. 169 (Study II, III and IV). In the light of this disruption most factors – such as social support, caregivers, misgivings, hope and/ or 'fighting spirit' – were connected to the amputation/ mastectomy itself and the lost body part. Significant loss had the power to threaten an accustomed way of life and provoke affects of sorrow or despair (103-106). That the loss of a limb influences and disturbs a person's everyday life is self-evident. What was very interesting in the present study was that irrespective of what body part, its loss also implied for many a great loss of personal identity (Study IV). Previously, it has been assumed that the significance of the breast for a women's female identity played a role in her experience of phantom breast phenomena (64, 107). However, the loss of identity was experienced and described more often by the women with breast cancer, although this loss was also described by the limb amputees, often together with the loss of function.

This grief and this missing of the former earlier less complicated everyday life, combined with a will and fighting spirit to compensate for the loss, can in part account for the toned-down descriptions of phantom phenomena as a hindrance in the amputees' way back to ordinary everyday life (Study III).

That pain and sensations can exist in a body part that isn't there differentiated this experience from other pain conditions. More than the phantom pain, the phantom sensations seemed to remind the interviewee of a body part so demonstrably lost (Study III). It was when describing their veridical body space with a particular size, shape and posture (their corporeal awareness) that their descriptions developed into accounts and narratives about the person they used to be, and the life the body part had helped them to live. This is the manner in which their loss was made visible (Studies I, III, IV) to a listener.

Despite the absence of negative reactions from the surroundings, a sense of being stigmatized is evidently associated with the loss of a body part (Study IV).

THE SIGNIFICANCE OF CURRENT PERCEPTION OF KNOWLEDGE AND A TIME-PERSPECTIVE

Current perception of knowledge

The interviewees described their peri- and post-pain treatment as surprisingly effective. Almost all described this satisfaction spontaneously. It seemed that this experiences inspired in the interviewees some trust and reliance that the present phantom pain would also be possibly manageable in the future, at least possible to live with (Studies II and III). Carr (108) has pointed out that little is known about patients' expectations and preferences regarding different pain-producing situations. Carr further underscores the importance of listening directly to the "patient's voice" for better knowledge concerning how to form the structure for the pain-treatment situation – and as a consequence the result.

All the present interviewees underwent amputation in a high-volume unit using surgical techniques that reduce the risk of chronic pain. Such factors have proved to have a significant impact on the development of neuropathic pain conditions in the cancer context (49, 56, 109). The hospital had guidelines for amputation and pain treatment although there was no guarantee that these guidelines were followed. Such procedures are significant for outcomes related to the development of neuropathic pain conditions (110).

It also became apparent that the interviewees were living in a 'medicalised' society (83, 111). Almost everyone accepted the current medical explanation model of phantom phenomena, which they had learned about from the health care system or elsewhere. However, the interviewees transformed this medical explanation into a comprehensible everyday explanatory model. But accepting the medical explanation as the valid one was insufficient to make one's own phantom experience understandable and meaningful. This elucidated a difference between the medical explanation and the everyday explanation and understanding (Study III). It also became obvious that evidence-based pain medicine is not enough to enable all patients to understand their phantom phenomena. This is an important observation, since in Studies I and III this incomprehensibility was related mostly and to a high degree to phantom sensations, rather than to pain (Study III). Phantom sensations are described as transient and a rare problem (40, 41). Perhaps they represent a far more complex problem, one that is being overlooked in the clinic?

Thus, the present findings indicate that the interviewees' current knowledge could influence their attitudes and approaches to the pain-producing situation and as such have significance for how they will experience the phantom phenomena.

Reflections concerning the time perspective

At individual level, already within the first month after the amputation/mastectomy a time perspective was discernable: the interviewees described their current pain and that it was changing over time (Study I). Not only this: pain intensities at the time of speaking were described. The interviewees also used a reflective approach to their different pain and sensory disturbances. Thus, there was a mix of states of pain, with current and/ or retrospective conditions being described in the interviews. This dynamic became yet more visible in Study II. Toombs (102), p. 228 has highlighted the importance of professionals understanding and respecting this temporal constituent in patients' descriptions of their illness, not regarding their experience as "a temporal entity". The present findings indicate that the patients' descriptions did not constitute such temporal entities, and this underscores

the importance of taking individual variation into account when assessing the level of reported perceived pain (77), p. 25. There is an inherent risk of over- or underestimating patients' perceived experience in medical clinics where visual analogue scales (VAS) are used as the only tool for intensity assessment (77) and in pain studies where structured pain questionnaires are the only instrument (82). The personal experience of a pain condition can be judged only by the person in pain, but it is important that her or his experience can be understood by the physician and other health personnel in the consultation.

When individuals describe their illnesses, the significance of the time perspective and earlier experience is obvious (6, 80, 91, 102). A central problem in illness narrative is that the narrator cannot foresee an end. This makes it difficult to evaluate and understand the illness symptoms "...because there is no temporal horizon to give them meaning" (6), p. 41. In the present studies it became evident that the interviewees had had experience of exceed and or treatable pain conditions but lacked corresponding experience for their phantom sensations. Could perhaps the absence of control and unending experience be the reason for triggering the phantom sensations more than the phantom pain?

From a societal, historical and cultural perspective time also has implications for how the amputation/mastectomy as a life-disruption, with its losses and its consequences, will be experienced. This in turn influences the afflicted person's possibilities to manage the situation. For example, the circumstances of the surgical processes and the rehabilitation situation will both differ greatly for the present interviewees from those of young victims in a war zone lacking medical facilities (112). It is important to include and take into account such sociocultural and economic influences to better understand the meaning of the phantom phenomena (7, 83).

REFLECTIONS CONCERNING THE SIGNIFICANCE OF THE BACKGROUND DATA

The purpose of including different causes of amputation, interviewees of both genders and widely varying ages was to get as much information as possible on how the interviewees described and experienced various types of phantom phenomenon without seeking causal associations between these factors and their phantom experience.

In addition, interesting findings were uncovered which can have significance both for the clinicians and for the design of future studies. For the older interviewees, extensive anxiety and big problems of lost mobility dominated at several levels (Studies I, III and IV). This tallies with the finding from other studies, where the older persons represent the greater proportion of amputees studied (12). However, generalizing can misleading here and should be avoided (113). Findings from Study II underscore the importance of being observant of possible phantom breast phenomena after breast surgery. The interviewees' knowledge of these phenomena was nearly nonexistent! Study III indicated in several ways the significance of the course of the disease preceding the amputation/mastectomy for the feeling of readiness for the decision about amputation/mastectomy. As described by (106), such a decision could be for some of the amputees with a diabetic/vascular disease more traumatic than the corresponding decision described by an interviewee amputated for actual trauma. The amputation could be experienced as a culmination of raised hope and disappointment (ibid., p 210).

Recently, three studies from different perspectives on pain (114-116) reported findings interesting for the present work. The age and gender differences in patients' descriptions of their pain experience could lie in their different ways of talking about pain, regarding the willingness both to report psychosocial triggers and to use evaluative words. All in the present great hindrance group were women, who also constituted the majority in the moderate group: while the majority of men were in the trivial or no hindrance groups. Notably, there was an almost negligible difference between the women's and the men's ratings of annoyance.

Study IV uncovered psychosociocultural factors and/or combinations thereof, which could be precarious and threatened to make some individuals vulnerable in their social surroundings. Such 'danger flags' were comorbidity, old age, early retirement, abrupt loss of social contact e.g. following a divorce, moving to a new area, poor economy and immigration from outside Europe.

”… är det inte spännande att tanken inte kan existera utan språk, och eftersom språk är en hjärnfunktion måste vi säga att språk – förmågan att uppleva världen genom symboler – på sätt och vis är en fysisk egenskap hos människan, vilket bevisar att den gamla kropp-själ dualiteten är rent nonsens, visst gör det? Adieu, Descartes. Kropp och själ är ett”

Paul Auster, Osynlig, 2010

METHODOLOGICAL CONSIDERATIONS

This qualitative interview study followed two different methods of analysis. More detailed descriptions of the processes employed are given the respective studies.
Open-ended, narrative-oriented interviews were found suitable when inviting people to use their own voices to describe their experience and its meanings (84, 87, 117). Transcribed verbatim, the interviews constituted the main data source for all the four studies. The interviewer started each interview by explaining the aim of the study and the four themes to be covered. She also stated that the selection of topics and the order were up to the interviewees. The interviewer followed up the interviewees' descriptions with additional questions, if something was unclear. The four themes acted more as a checklist to ensure that similar topics were covered in all the interviews (117).

STUDY I AND STUDY II.

The transcribed interviews were analysed with a combination of narrative and discursive methods concerning the total sample of 28 interviewees one month after surgery (Study I), and in Study II concerning the eight women with breast cancer; likewise for the further three interviews (six months, one and two year after the mastectomy).

STUDY III AND STUDY IV

Since the present design was longitudinal and the aim was to analyse all the interviews during the two-year period, content analysis appeared appropriate. This type of analysis allows systematic comparison of differences between individuals and of individual differences/changes over time (96). When using content analysis it is important to decide whether to analyse only the manifest content or the "latent" content as well (98). Thus the themes and categories were analyzed from the open-ended interviewees. For example, within categories not mentioned by one or several interviewees factors of uncertainty arose and were marked with a 'non-existent description' (NED). There could be many reasons for this "silence". Because of its less standardized character, content analysis is a complex challenging and time-consuming process comprising a number of phases (87, 96, 98, 118). It does, however, have possibilities to summarize patterns within often unique sets of data (118).

Conclusion and clinical implications

The present findings confirm the importance of listening (without pre-designed questionnaires) and carefully analysing patients' own descriptions of their phantom phenomena: this to acquire new understanding of the phenomena and how to treat them. There is a great need to create prerequisites for a real dialogue between patient and health care provider before and after an amputation and a mastectomy.

Together, the findings elucidate the importance of this individual approach to the phenomena as an on-going process of evaluation and selection. Equally important is the awareness that experience and understanding of phantom phenomena also have sociocultural roots. Perception and tolerance of pain are not purely physiological responses and the patient's reports embrace more than an objective reaction to their physical condition (119). This further emphasises the clinician's need for individual communication and information. The present insights may be useful when encountering other iatrogenic pain conditions.

Future research

The findings highlight the need for a social-scientific and meaning-centred approach in future studies of both phantom phenomena and also of other pain conditions. Future research here must adopt a more multidimensional perspective on research methods (50, 73). Other qualitative research approaches that admit individual variation when including narratives could be one way of creating a standard for assessing and evaluating phantom phenomena. But study designs that constructively distinguish between phantom sensations as sensory transducers and as corporeal awareness (39, 69, 120, 121), can also bring worthwhile understanding of amputees' experience of their phantom pain.

SVENSK SAMMANFATTNING
(POPULÄRVETENSKAPLIG FRAMSTÄLLNING)

Smärta är ett komplext fenomen. Inget annat fenomen inom sjukvården öppnar så för oss att komma nära människan så väl i hennes biofysiologiska som psykologiska, sociokulturella och existentiella varande som just smärtan och dess många uttrycksformer. Forskningen runt smärta, dess orsaker och konsekvenser har de senaste 40 åren varit intensiv inom ett flertal olika vetenskapsdiscipliner. Många landvinningar har gjorts. Och behandlingsmöjligheterna för olika smärttillstånd har i betydande grad förbättrats de senaste årtiondena. Men ännu återstår dock ett flertal olika smärttillstånd, som saknar tillfredsställande behandlingsförslag.

Fantomfenomenet, ett väldokumenterat post-operativt smärttillstånd, är ett sådant exempel. I detta fenomen inkluderas såväl smärta som andra sensationer (exempelvis klåda, tryck, obehagliga lägen eller rörelser) i den bortopererade kroppsdelen. Den borttagna kroppsdelen upplevs då av den amputerade som lika befintlig och verklig, som när den fanns på plats. Både i klinik och i ett flertal studier beskrivs, hur den amputerade bestämt hävdar, att det inte handlar om en ”som om” upplevelse: deras förlorade kroppsdel *är* där. Förutom fantomsmärta och fantomsensationer brukar smärta i kvarvarande stump/operations område noteras och värderas, när man i kliniska eller vetenskapliga sammanhang försöker ta reda på fantomfenomenets intensitetsmässiga betydelse för patienten.

De allra första vetenskapligt framtagna kunskaperna kring fenomenet hade sin upprinnelse i krigets konsekvenser. Två läkare, en kirurg (Ambrose Paré 1551) och en neurolog 300 år senare (Silas W Michell 1871) har båda, utifrån sina, respektive, mycket omfattande material, dokumenterat och beskrivet såväl förekomst som olika uttrycksformer för de drabbade soldaternas fantomsmärta och fantomsensationer. I mycket hög grad överensstämmer dessa läkares beskrivningar, när det gäller såväl förekomst som uttrycksformer med vad som framkommit i långt senare studier.

Rapporterad förekomst av fantomsmärta är: 60 – 80 % hos de extremitetsamputerade. I longitudinella studier har fantomsmärtan visat sig kunna kvarstå upp till två år hos 60 – 75 % av fallen. Förekomsten av fantomsensationer rapporteras hos de extremitetsamputerade nästan upp till 100 %, men fantomsensationerna har också beskrivits som avklingande över tid samt att inte utgöra något större problem för patienterna i klinik.

Vad som har förändrats över tid är olika förklaringar till själva fenomenet. Idag betraktas som konsensus (vetenskapligt belagd överenskommelse) inom smärtvärlden: att uppkomst och eventuellt vidmakthållande av fantomsmärta och eller fantomsensationer handlar om flera komplexa interaktioner i det centrala nervsystemet: såväl det perifera systemet, som ryggmärg och hjärna är involverat. Framsteg inom neuroradiologin: magnetisk resonansstomografi (MR) och positronemissionstomografi (PET-scan) har kunnat påvisa att olika områden i själva hjärnan är samrelaterade på ett mycket komplext sätt, när det gäller fantomupplevelserna. Detta är mycket viktiga resultat, men likväl har de inte förutsättningar att åstadkomma en kunskap som verkligen kan tala om, hur fantomfenomenet upplevs av den individuella patienten i hans vardag. Likaså har utvärderingsinstrument med i förväg bestämda variabler vissa begränsningar i att åstadkomma direktklinisk användbarhet, hur värdefulla de än är som screening instrument.

Den kunskap som finns kring fantomsmärta och fantomsensationer handlar till största delen om konsekvenser efter amputation av armar och ben men fenomenet finns, om än i mindre utsträckning, även beskrivit efter t. ex bröst-, genitalier-, rectum- och tandkirurgi.
Trots intensiv forsknings saknas fortfarande väsentlig kunskap kring hur den enskilda individen i vår samtid upplever sin fantomproblematik och i vilken utsträckning fenomenet innebär ett lidande och hur detta i så fall ser ut.
Syfte med denna avhandling var att få kunskap och förståelse för hur amputerade människor beskriver sina fantomupplevelser, när de får utgå från sina egna vardagliga erfarenheter och använda sina egna ord. Vi ville också försöka få en inblick i vilken utsträckning deras beskrivningar påverkades av olika sociokulturella faktorer. Med denna forskningsansats var vår avsikt att söka kompletterande kunskap till redan befintlig kunskap, som dock övervägande är av neurobiologisk karaktär.
När man vill beforska mänskliga erfarenheter, hur individer tillskriver dessa erfarenheter en mening, samt hur de hanterar dessa erfarenheter, är kvalitativa forskningsmetoder är de mest användbara. Intervjuer med öppna, narrativt- orienterade frågor riktade till ett begränsat antal individer, som varit exponerade eller involverade för samma händelser, är en lämpliga sådan metod. Sådana utförda och transkriberade intervjuer utgjorde huvudmaterialet för studierna i denna avhandling. 28 män och kvinnor i olika åldrar och med olika bakomliggande orsaker till sin amputation/bröstkirurgi ingick i studien: cancer (sarkom respektive bröstcancer; vaskulära sjukdomar/diabetes; och trauma). Frågeställningar och analys metodmetod inom de olika arbetena skilde sig delvis åt
Följande resultat från de olika studierna kan betraktas som intressanta i förhållande till avhandlingens syfte:
Fantomsensationerna upplevdes i mycket högre grad som obehagliga än vad fantomsmärtan gjorde. Det fanns en upplevelse av obegriplighet kring dessa sensationer samt en oro att de inte skulle kunna gå över.
En månad efter amputation/bröstkirurgi beskrevs sällan själva fantomfenomenet som ett hinderför intervjupersonernas återgång till ett ”normalt” liv igen. Detta trots att intensiteten hos såväl fantomsmärta som fantomsensationer beskrevs som mycket hög. Det framgick tydligt att själva amputationen för de allra flesta av de intervjuade, oavsett tidigare sjukdomstillstånd och orsak till amputationen, upplevdes som ett livsavgörande avbrott i deras pågående vardag – ett avbrott i allt man tidigare ”tagit för givet”. Det var kring amputationen/bröstkirurgin som intervjupersonerna formulerade och beskrev tankar och känslor, som kan sägas ge en bild av det individuella lidandet. Sådana beskrivningar var ytterst sällan relaterade till fantomsmärtan eller fantomsensationerna i sig. Däremot gav intervjupersonernas ingående beskrivningar av sin förlorade kroppsdel och vad den hade betytt för deras föregående liv. Detta utgjorde en stark indikation på att förlusten av denna kroppsdel för dem kunde betyda både förlust av för dem meningsfull funktion och känsla av identitet. Det framgick också tydligt, att för de äldre personerna innebar kroppsförlusten och den minskade rörligheten på flera plan en så mycket större oro och ängslan än för de yngre.
Det visade sig också, att det var mycket svårare för de kvinnorna som upplevde någon form av bröstfantom, att beskriva dessa upplevelser, än vad det var för de extremitetsamputerade. Den information (både vad gäller fantomen som eventuell konsekvens och dess orsaker) som de flesta extremitetsamputerade fått av primäransvarig läkare, saknades helt för kvinnorna med bröstcancer. De hade också i mindre utsträckning hör talas om fantomfenomenet via andra kanaler. Då hälften kvinnorna med bröstcancer hade upplevelser av en bröstfantom

syns det viktigt att man inom sjukvården i högre utsträckning informerar om fenomenet som en möjlig (om än ovanlig) konsekvens efter bröstkirurgin.

Sammanfattningsvis: För att förstå individen och hans/hennes fantomproblematik räcker det inte enbart med att efterfråga eller mäta intensitet hos fantomsmärtan/fantomsensationerna. Viktig kunskap kring eventuellt lidande som kan interagera med fantomupplevelserna bör fokusera mot amputationen/bröstkirurgin som en livshändelse av stor betydelse för den drabbade. Individen beskrivning av kroppsförslutens betydelse för honom/henne kan ge värdefulla nycklar till att förstå vad som på ett individuellt plan kan påverka patientens beskrivning av sin smärtupplevelse. Det är också viktigt att känna till den samtid individen lever i för att få kunskap om just hennes unika smärtupplevelse. Vilken kunskapssyn och vilka medicintekniska resurser finns tillgängliga och hur kan dessa påverka individens uppfattning och förhållningssätt till sig själv och till sina fantomupplevelser? Sådana sociokulturellt betingade förutsättningar är med och påverkar vilken betydelse fantomsmärtan/fantomsensationerna får i den drabbades vardag. Dessa insikter kan också vara giltiga för förståelsen av andra behandlingsrelaterade och eller långvariga smärttillstånd.

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